

VOLUNTARY BUYOUT

More than 2,000 State Workers Involved in Budget Reduction

More than 2,400 Division of Mental Retardation Services (DMRS) employees right now are making one of the most important decisions of their lives: Whether to accept an invitation to leave their jobs for financial and educational benefits. Their positions could be eliminated as the State is reducing \$64 million dollars in recurring



Giant screen used for video viewing at Greene Valley.

expenses from the annual budget. DMRS issued the large number of invitations in hopes of getting 185 acceptances.

“This is a very personal decision for our employees who received an invitation,” said DMRS Personnel Director Karen Haynes. “They must look at their situation, personally and professionally, and decide if this program is right for them. We encourage those persons to thoroughly review the material they received and not hesitate to do research and ask questions.”

It is called the Voluntary Buyout Program (VBP). Overall, during the middle of last month 12,000 Executive Branch employees received invitation packets with the State seeking 2,200 positive



DMRS Deputy Commissioner Stephen H. Norris speaks to Greene Valley employees.

replies. The elimination of positions accompanies operational budget reductions made in State agencies, a result of a major shortfall in revenue collection. Tennessee reduced its FY 2008-2009 by nearly \$500 million.

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The Artist's Voice: An Exhibition Featuring Tennessee Artists with Disabilities

The Artist's Voice: An Exhibition Featuring Tennessee Artists with Disabilities is showing at The Frist Center for the Visual Arts in Nashville. The exhibit is located in the Conte Community Arts Gallery. The



Howie Bryant, Clover Bottom Developmental Center.

exhibition presents more than 50 paintings, prints, sculptures, digital art and documentary film created by 54 Tennessee artists, who each live with a disability. The artists and their works were selected by a juried panel from more than 400 submissions. Admission is free for this exhibition, which will continue through Sept. 14, 2008.

Residents at Clover Bottom Developmental Center are represented in the exhibit. An example of the transformative power of creativity is seen in the work by the CBDC artists. Many of the non-verbal residents, as well as those facing other communication challenges, respond to color, shape and texture. Their intricate sculptures, which are made of wood with polymer clay or brightly

colored felt, are testimony to the idea that art offers vision and voice to the silent and misunderstood.

“The works in The Artist's Voice are a testament to the power of art to eliminate

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Open Wide!

- The Artist's Voice
- Reimbursements and Federal Funds
- MegaConference
- Rescuing Rex

From the Desk of Deputy Commissioner Stephen H. Norris

I hope everyone had a nice and safe Fourth of July. Whatever festivity you partook – picnicking with friends and family, watching fireworks – I hope it was most enjoyable.



The Division of Mental Retardation Services (DMRS) got an early start on the holiday as the past several weeks we have seen our share of unintended fireworks. Mix a State Comptroller's audit and the inaccurate media coverage and errant word-of-mouth and you have a highly combustible situation with a short fuse. Hopefully at the end of this column the record will be set straight and this fuse doused.

The State Comptroller's audit covering the period of April 1, 2005 through May 31, 2007 was issued several weeks ago. DMRS' presence in the audit generated much talk and media attention and the more the information was circulated the more it became misconstrued. There were several audit findings, some of which DMRS took exception. However, we view audits in a positive light, considering them a management tool with problems being identified and corrective action recommended. DMRS had resolved most of the items noted in the audit and took serious measure of the others that remained.

One topic gained prominence over others and caused concern. Auditors maintained that DMRS failed to collect federal reimbursement for waiver services, costing taxpayers millions of dollars. The exact figure was \$67 million which was a receivable and ultimately a bad debt originating from denied claims.

From 1997 until late 2003 this issue was not addressed and essentially lay dormant. I joined the Division in October 2003 and soon after began bringing on key personnel to assist in addressing the Division's problems and issues. Soon, for the first time DMRS had its own administrative arm.

As we focused on reimbursements we basically had to start from scratch, identifying the problems and developing a system for correction. Over the past years new mechanisms have been implemented to target errors in filing: Audit and Denied Claims units were formed, eligibility determination counselors were hired and an electronic billing system was devised.

During Fiscal Years 2004-2005 and 2005-2006 we elevated our monthly collection rate from approximately 92 to 95 percent to between 95 and 98 percent. Yes this was improvement, but it was also the maximum result we were going to achieve utilizing present tools. Something else had to be done to move from this point.

In the fall of 2006 we decided to alter the reimbursement process to providers so that no state dollars were paid until the claims were deemed appropriate by the DMRS and TennCare electronic billing systems. Following six months of system changes and testing the new payment process went into effect on July 1, 2007.

By any examination the one-year-old process is working very well. The collection rate is approximately 99.5 percent. The current payment system is not only more accurate, but eliminates the possibility of an accumulation of denied claims and bad debt.

I am not enlightening anyone when I say the provision of services for Tennesseans with mental retardation is complex, consisting of a myriad of systems, components, rules and regulations. It can be difficult, even for those of us working in the field. The uneasiness created by the State Comptroller's audit and the subsequent dissemination of information by media and word-of-mouth is a perfect example of the difficulty in understanding the intricacies of our business.

You, our stakeholders, know the progress that has been made over the past five years. Nursing to health an ailing system while under litigation has been a challenge. However, working together we have fostered success. From the beginning I have striven to solicit and include your input in the Division's practices. Open communication is crucial as we meet and address future challenges. It is vital as we confront and allay fears and misperceptions like the ones created by the media coverage of the audit findings.

I have spoken often of the commitment and dedication of DMRS staff. Our service recipients are the reason we are here. Everything we do is for the betterment of their lives and there is no relaxation in our work. There may be errors along the way, but have no doubt those mistakes will most certainly originate from the effort to do better. ■

THE 2008 TENNESSEE DISABILITY MEGACONFERENCE

Peggy Cooper, The Arc of Tennessee

We just ended our sixth annual statewide Tennessee Disability MegaConference. There were over 900 attendees this year. There were 28 partnering agencies, 59 exhibitors, over 100 presenters and a truckload of volunteers!

Keynote speakers this year were Michael May, who holds the record for downhill skiing by a totally blind person (racing at 65 mph); Nelson Lauver, who overcame illiteracy forced upon him by Dyslexia; and Juliette Rizzo, Miss Wheelchair America. There were over 90 breakout sessions and times scheduled for organizations to hold meetings. Continuing education credits were offered in six professions.

"The MegaConference has become sort of a family reunion. It is an opportunity to connect with people you only see once each year and to catch up on each other's lives, family and significant events," said Wanda Willis, executive director of the Tennessee Council on Developmental Disabilities and co-chair of the Accessibility Committee.

Jane Smith of People First said that she really looks forward to the conference every year. She loves the night time activities like karaoke because they are fun and give people time to socialize. She said that they really enjoy the band Boomerang and dancing to their 60's sound. She also looks forward to the information sessions because there is always something that she needs to learn. She loves sharing "People First Language" with others.



Scott Finney and Sondra South rock the house on karaoke night.

People who ordinarily would not get to, got to swim because appropriate supports were in place.



Lorri Mabry floats with the help of Karen Nelson, therapist.

Awards were given by The Arc of Tennessee, the Direct Support Professionals Association of Tennessee and STEP (Support and Training for Exceptional Parents) at the Awards Banquet and Dance.



John Clayton, DSPAT; DMRS Deputy Commissioner Steve Norris; David Almonrode, Hilltoppers Inc; and Earl Foxx, DSPAT Executive Director.

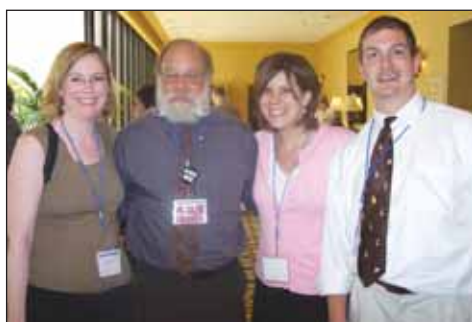
Siblings and families attended the conference together.



Merry Jensen and Ruth Roberts attend the conference together annually.

Tennessee is truly blessed to have many strong disability organizations and state agencies that are willing to work together. Our shared missions bond us and our passions strengthen our ability to provide a quality convention that offers stipends to people with disabilities and their families

who may not otherwise be able to attend. It takes a clock-full of hours, much dedication and plenty of patience to pull off a conference of this magnitude. There are many behind-the-scenes details and actions that take place even during the actual conference that are not transparent to attendees.



Gina Lynette, DMRS; Steve Jacobs, The Arc of Tennessee (Program Committee Chair); Courtney Jenkins-Atnip, Tennessee Disability Coalition (Hospitality Committee Chair); Frank Meeuwis, The Arc of Tennessee (Event Sponsorship Co-chair).

"We are proud that we have been asked to share our planning processes with other states who want to model conferences after ours. The Arc of Oregon has already tapped into our resources and is now hosting its own version of a mega conference. Our hope is that people appreciate what we are doing for Tennessee and understand the value of the MegaConference," stated Walter Rogers, executive director of The Arc of Tennessee and chair of the MegaConference Steering Committee.

People always ask a lot of questions about "how we do it," so here are some tidbits:

How long does it take to plan a conference like this? It is an ongoing process. As soon as the conference is over, we compile evaluation information and hold a "debrief" meeting. We take attendee feedback into consideration and immediately begin planning the next conference.

How are duties assigned? Who does what? We operate through committees. Each

THE 2008 TENNESSEE DISABILITY MEGA CONFERENCE CONTINUED

committee has a portion of the conference they are responsible for. Duties within committees may be divided by individuals to complete particular tasks. Our committees are: Steering, Exhibits, Accessibility, Event Sponsorship, Hospitality, Local Arrangements, Program, Public Relations, Registration and Stipends, Respite, and Volunteer.

How often do committees meet? Most committees meet monthly and committee chairs make up the Steering Committee that meets monthly.

Is there a website? Yes <http://www.tndisabilitymegaconference.org>
The website contains all conference information and includes the duties of the above mentioned committees. We recommend that people check the website often for updates.

Whom do I contact if I would like to serve on a committee?

Contact the committee chair of your area of interest.

When does the call for partnering agencies go out? Last year the call went out in the fall asking partners to sign up by the end of the year. It is helpful in developing a realistic budget to know our partners and their level of monetary commitment early. This too is an ongoing process and we always welcome new partners every year, even if they do sign up late!

When does the call for speakers usually go out? What topics are sought? You can expect the call to go out in the fall. Usually speakers have been selected by the end of the year. Topics include: Access, administrative/management, assistive technology, disability specific, education, employment, empowerment, interactive, quality supports, recreation, relationships and sexuality, and systems change.

When can I register or apply for a stipend? Registration information and stipends applications are released in the early spring. Email notices will be sent out, and the forms will be posted on the website and included in newsletters.

How is information about the conference distributed? Emails (email pcooper@thearcctn.org to get on my distribution list), Yahoo listserv (go to <http://groups.yahoo.com/group/MegaConference/> to join), newsletters, word of mouth, and meetings.

Why is the conference always in Nashville? Because our state is so long, Nashville is a central location. It would be very difficult for people in East Tennessee to attend a conference in West Tennessee or people in West Tennessee to attend a conference in East Tennessee because our state is over 500 miles wide!

Why is the conference usually at the Airport Marriott? Because the Airport Marriott offers complimentary accessible airport shuttle service for our keynote speakers and has the greatest accessible sleeping room ratio than any other hotel in Nashville. They also willingly work closely with us to provide extra supports and special requests for people with disabilities.

On behalf of everyone involved, I'd like to take this opportunity to offer thanks, salutes and pats on the back in no particular order to:

- All conference partners for contributing to the cause
- The therapists from Clover Bottom for helping with the swimming and providing equipment
- Permobil for providing the T-shirts
- Elizabeth Bishop and Karen Nelson for coordinating the Continuing Education Units certification
- League for the Deaf and Hard of Hearing for providing interpreting services
- Progress, Inc. for providing respite services
- Tennessee Disability Coalition for the goody bags
- Committee chairs and volunteers who worked "MegaHours"
- Nashville Airport Marriott for giving us discounts and working closely on disability details
- All exhibitors for sharing their products and services
- All attendees for coming and sharing your wonderful comments with us
- And most of all my co-workers at The Arc of Tennessee for putting up with me all year long! ■

Buyout...cont

"The workforce reduction could have been achieved by layoffs," said DMRS Deputy Commissioner Stephen H. Norris. "However, Governor Bredesen chose to address this issue through the Voluntary Buyout Program. The program is being conducted in a way that is fair and respectful to employees."

Statewide information sessions for invitees concluded recently. Norris and Haynes made presentations, which included a video, at Arlington, Clover Bottom and Greene Valley Developmental Centers, and the DMRS Central and East Regional



DMRS Personnel Director Karen Haynes conducts a Greene Valley question and answer session.

Offices. Department of Human Resources Commissioner Deborah Story traveled the state meeting with staff from other agencies.

"A large number of employees at the facilities and out in our regions received packets, so it was better that DMRS personnel met with them," said Haynes. "Also, Deputy Commissioner Norris wanted to be present for the sessions." Persons who would like to participate in the buyout must have their applications submitted by August 5th. Those persons accepted into the program will be notified on August 11th.

For complete Voluntary Program Buyout information call 615-253-9980 or toll free at 866-252-7954, visit the website at

Buyout...cont

www.tn.gov and click on the gold button noted “Voluntary Buyout Program” or email

Voluntary.Buyout@tn.gov. ■

SIGN UP TO ATTEND A VBP HELP SESSION

The application deadline for the Voluntary Buyout Program (VBP) is quickly approaching.

Applications must be postmarked or hand delivered to the Department of Human Resources by 5 p.m. CDT on Tuesday, August 5.

To ensure employees eligible for the VBP have as much access to information as possible, a series of VBP Help Sessions will take place across the state will begin in mid-July. Unlike the large group employee information sessions held in June, these VBP Help Sessions will give VBP-eligible employees an opportunity to meet one-on-one or in small groups to ask questions and obtain additional information.

Who should attend?

- Those eligible for the VBP who have questions about the program. Employees eligible for the VBP received a packet of information that was mailed to their home address.
- Those who have already applied for the VBP, or intend to apply. Obtain information and assistance completing forms that employees accepted for the VBP will need to make a smooth transition from state employment pertaining to health insurance, retirement, and other state benefit plans.

There is no guarantee of acceptance into the program. Those who apply for and are accepted will be notified around August 11th and the Voluntary Separation Date for most employees accepted will be August 15, 2008.

What do I need to do to attend?

So we can serve as many employees as efficiently as possible, please sign up for a VBP Help Session by emailing: Voluntary.Buyout@tn.gov.

Appointments will be scheduled throughout the hours indicated in the schedule. Please provide your name, department, and the date of the meeting and time you would prefer to attend.

VBP eligible employees should obtain approval from their supervisor to attend a VBP Help Session during scheduled work hours. While administrative leave will be granted for those with supervisor approval, travel and mileage expenses will not be reimbursed.

Remember, if you received an invitation only you can decide if the VBP is right for you!

VBP Help Session Schedule

- | | |
|---------------------------|--|
| Thursday, July 17 | Nashville – Snodgrass Tennessee Tower
312 8th Avenue North
Hours: 12 noon to 6:00 p.m. CDT |
| Monday, July 21 | Nashville – Department of Labor & Workforce Development
220 French Landing Drive
Hours: 12 noon to 7 p.m. CDT |
| Tuesday, July 22 | Memphis – Tennessee Career Center at Memphis Raleigh
2850 Old Austin Peay Highway, Suite 132
Hours: 12 noon to 7 p.m. CDT |
| Wednesday, July 23 | Jackson – Tennessee Career Center at Jackson
362 Carriage House Drive
Hours: 12 noon to 7 p.m. CDT |
| Thursday, July 24 | Columbia – Tennessee Career Center at Columbia
119 Nashville Highway, Suite 106 (Northway Shopping Center)
Hours: 12 noon to 7 p.m. CDT |
| Monday, July 28 | Johnson City – Tennessee Career Center at Johnson City
2515 Wesley Street
Hours: 12 noon to 7 p.m. EDT |
| Tuesday, July 29 | Knoxville – Tennessee Career Center at Knoxville
1610 University Avenue
Hours: 12 noon to 7 p.m. EDT |
| Wednesday, July 30 | Chattanooga – Tennessee Career Center at Chattanooga
1105 East 10th Street
Hours: 12 noon to 7 p.m. EDT |
| Thursday, July 31 | Cookeville – Tennessee Career Center at Cookeville
3300 Williams Enterprise Drive
Hours: 12 noon to 7 p.m. EDT |
| Monday, August 4 | Nashville – Snodgrass Tennessee Tower
312 8th Avenue North
Hours: 12 noon to 5 p.m. CDT |

Maps and directions can be found on the VBP Web site. Just go to www.tn.gov, click on the gold button that says Voluntary Buyout Program, and then select “VBP Help Sessions” on the left menu bar. ■

"What are you doing?" "Am I alright?" "Are you alright?"

Walter Hensley



I have lived most of my life in the Atlanta, Georgia area. After experiencing a very heartbreaking and difficult time in my life, the details of which are not important to this letter, I moved home to Kingston, Tennessee seeking to put my life in perspective. Very recently I met a special neighbor. This person has helped me gain new hope and direction. This neighbor is a young man around 30 years old whose name is Eric. Eric lives about a mile from me in a home which is staffed by employees of the Michael Dunn Center so that he can live as independently as he can.

As I walked toward Eric for the first time I felt a little nervous, realizing he was in a wheelchair. I also felt a bit afraid I would not have the correct words to say to him. My fears were quickly put to rest when I came into his presence. Before I could greet him – He greeted me with a loving and enthusiastic "Hi" and with an extended hand. As I reached to shake his hand and say hello, he quickly grasped my hand with another "Hi". Instead of shaking my hand he held it, looked up at me and greeted me with a smile that melted my hardened heart. He then asked me, "What are you doing?" I hesitated in surprise and then answered, "Just visiting with you". He replied again with his beautiful smile. A smile so genuine and loving it changed my whole attitude that day.

We continued our visit on this beautiful spring day. At one point the sun got in his eyes and he sneezed. The sneeze was then followed by the question, "Am I alright?" His caregiver answered him, "You're alright." Eric then asked his caregiver, "Are you alright?" He was answered with "Yes, Eric, I'm alright". He asked these same three questions many times during our visit.

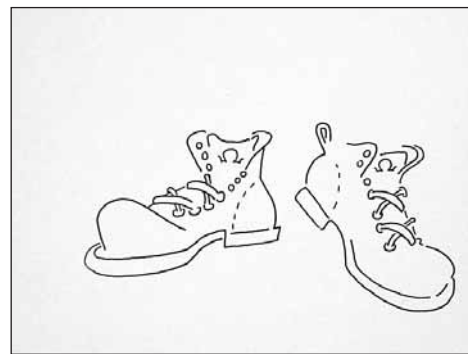
As I sat there with Eric on this beautiful day a revelation began to come to me. Not only is he alright, but probably more so than anyone I have met in a long time. Upon first looking at Eric you may see a person in a wheelchair, a person with limited physical abilities, a limited vocabulary, and limited mental capabilities. Yet upon being with him a few minutes – I began to see a person with such a sweet loving spirit and so very happy within himself. This made me ask myself, "Am I alright?" I get caught up in my daily routine and my everyday concerns in life. I often do not greet people with a handshake or even a smile. I rarely ask others "What are you doing?" and "Are you alright?" I realized how much I take the blessings in my life for granted. Here, it would seem, is a person I should pity – WRONG! This is a person I now truly admire, as well as the caregivers at the center who make it possible for him to be our neighbor.

So, before we start out our doors to the regular routine of daily life, perhaps we should ask ourselves, "What am I doing?" "Am I alright?" and ask those we come in contact with, "Are you alright?" Such simple questions can change our whole attitude from worry and despair to Love and Gratitude. When words escape us a simple, "Hi" and a loving smile can be a blessing to those we come in contact with each day. We have some special, wonderful neighbors in our midst that most of us will never meet. I pray that God will bless these residents, as well as their caregivers at the center.

Now once again I ask you Eric's simple question, "What are you doing?" ■

The Artist's Voice...cont.

barriers as it offers healing, strength, and encouragement to its creators, while giving voice to the varied lives of these resilient artists," said Anne Henderson, director of education at the Frist Center. "



Yancy Minnis, Clover Bottom Developmental Center.

The pieces featured in the exhibition have an expressive force and sense of beauty that rise above limitations that might be imposed by their artists' disabilities. Some of the works explore an artist's daily struggles of living with a disability; others convey a positive outlook, rich with vitality that is often achieved through using bright, bold color. Intertwining themes of strength, resilience, fragility, contentment and endurance can be seen throughout the exhibition. Though each work stands on its own artistic merit, the individual stories of their creators make the art even more engaging and awe inspiring.

The artists in this exhibition are motivated to make art for many reasons. Some use the creative process as a means of coming to terms with their particular situations and the world, while others use art as an escape from it. They attest to the therapeutic value of art and maintain that creating it assists them in their personal efforts to heal, live, and flourish in the world at large.

Last summer, the Frist Center solicited a Call for Works to receive entries for this exhibition, open to Tennessee artists, ages 18 years and older who have physical, cognitive or mental disabilities. Submissions were reviewed and chosen by a selection panel.

The Artist's Voice is sponsored by HCA and the TriStar Family of Hospitals. This project is also supported in part by an award from the National Endowment for the Arts. ■

Medical Message

Dr. Adadot Hayes, M.D., DMRS Medical Director

Good Health. What Is It?

Health, as defined by the World Health Organization is “a state of complete physical, mental or social well-being and not merely the absence of disease or infirmity.” Health is a dynamic condition resulting from a body’s constant adjustment and adaptation in response to stresses and changes in the environment to maintaining an inner equilibrium called homeostasis.

Health is different things to different people. One can have a significant disability or chronic disease and still be relatively healthy. One, also, can have no chronic problems or impairments and be in very poor health. In a sense, “health is what you make” and in this sense, people are greatly responsible for their own health. That means your doctor your partner and not the person who primarily manages your health (contrary to what most people believe). It is important that everyone understand what health is for them and how to manage it. Fortunately, there are many resources.

In addition, health is not just when you get sick and go to the doctor or take a pill, but is part of your entire life and needs to be integrated everywhere. Health affects and is affected by everything you do. Think about it. If you have diabetes, you don’t leave your diagnosis parked at the door when you go to work and eat donuts all day. If you are having trouble with something (work, relationship, child, etc.) it is possible that stress will affect your eating and sleeping which can impact your health and well being.

Emotional states have significant bearing on health and well-being, both positive and negative. It has been shown that death rates fall before important events as people “hang on.” Physical status and environment have effects, too. Just think about the Katrina trailers and the effect they had on many persons’ health.



Dr. Adadot Hayes, M.D.
DMRS Medical Director

So, even though you might not think about it specifically, health impacts all aspects of your life. Because of this, often we need to think very carefully about how we plan for aspects of our own health. This would include how we eat and sleep, our work and living environments, who we might see for a doctor, if we have health insurance, where we might go to the hospital, what we’d do for an emergency, how we handle anger, how we eat, our activities, our social activities and even where we might go to church or engage in other spiritual activities. Current models of health and health care include all aspects of life such as biology and life course, social and physical environment and lifestyle and behavior.

Along these lines you might want to be aware of national goals. Starting in 1980 following the surgeons report about the health of the nation, a new plan has been developed every 10 years. The current plan is Healthy People 2010, (www.healthypeople.gov). This plan provides a framework of prevention for the nation. The overarching goals are to increase quality and years of healthy life and to eliminate health disparities. Some of the focus areas include physical activity and fitness, food safety, environmental health and medical product safety.

But most of us think about health on somewhat narrower planes and may think about health as how our experiences occur as a patient. We pretty much have experiences and think about ourselves as a

patient in three areas – acute issues (cut finger, broken arm, flu, vomiting), chronic issues (high blood pressure, diabetes, bipolar disorder, GERD) or prevention (exercise, routine colonoscopies, immunizations, diet). Obviously, the less pressing an issue is, the less we pay attention. That’s where planning takes on importance.

In addition there are a whole host of other issues affecting us which we might not think much about. This might include insurance issues, emergency procedures, hospital competence, medication side effects, product safety issues, end of life issues and medical product safety issues. Almost 100,000 people die a year from medical mistakes and there’s a lot we can do ourselves to prevent this. A good book to help begin to think about these issues is *You, the Smart Patient* by Michael F. Roizen and Mehmet C. Oz. Important issues such as picking a doctor, how to pick a hospital, patients rights and alternative medicine are discussed. This book was sponsored by the Joint Commission (JCAHO), an organization that rates hospitals.

Other very important issues for people to consider in relation to health are medical records and how to find reliable information. Most adults have seen many doctors over the course of their lives, had tests done in various labs and hospitals and taken several medications, some of which may have had side effects. This information is not kept together by anyone unless you arrange to do so yourself. While all clinicians have records in their office only the patient can obtain them (or have them sent somewhere) so you are responsible. Unless you have a pretty good memory, it may be difficult to remember it all. (When did you have your last tetanus shot – recommended every 10 years and it is the adults who get tetanus, not kids.)

There are many resources to help you keep track of your medical history. A health journal titled *Keeping Track of Your Health* is available at www.jcrinc.com/t and there are several sites on the internet that will store information for you (you usually have to input the information) such as Revolution Health or Microsoft HealthVault.

RESCUING REX

A Story of Hope, Struggle and Success

Rex Smith has a way with women.

"The first time I met Rex he got right inside my heart," says Becky Johnson of Little Rock, Arkansas.

Check out the gushing of Melissa Landis of Knoxville whose first encounter with Rex was like a religious experience: "I got weak-kneed; he looked just like an angel!"

How many guys dream of having the ability to cast a spell like that? That's right. All of us! However, this story isn't about Rex Smith being a ladies' man, which he very much is, and a man's man too. This story is about a very special person who has overcome mountainous challenges to have a life and the two very special people who helped him scale the heights.

Some years ago the advocacy group, People First, sued the State of Tennessee charging violations of CRIPA, the Civil Rights of Institutionalized Persons Act. Greene Valley Developmental Center was named in the litigation. A settlement agreement was reached, and a Quality Review Panel (QRP) was formed to monitor the State's compliance in implementing the terms of the agreement.

Becky Johnson has had a long and successful career in mental retardation advocacy and case management. She was appointed to the QRP, which led to her introduction to Rex Smith.

From the moment Rex Smith was born he was on the downside looking up. Diagnosed with developmental disabilities his problems were compounded by head injuries sustained in a car wreck when he was three-years-old. With no father in his life and a mother with numerous personal issues, Rex was taken in by his grandparents.

Rex has Autism and Bipolar Disorder. As you will learn he has had behavioral issues that would test the most dedicated, strongest and bravest person. It wasn't long before he was too much for his



A young Rex at Greene Valley Developmental Center.

grandparents to handle. That's when Rex, at age five, became the youngest resident at Greene Valley Developmental Center.

"I had become a member of the QRP and was touring Greene Valley for the first time," said Johnson. "I met Rex, he was the only child in this institutional setting and I had a different dream for him. That was a life full of friends, baseball games, dances, work, and I wanted to make that dream happen."

Easier said than done. When Johnson met Rex he was eleven-years-old. Testing showed his communicative skills were one year, two months and his adaptive behavior one year, nine months. A psychologist's report noted he was very difficult to supervise and near impossible to teach.

"Rex was a challenge beyond imagination," said Johnson. "He was physically aggressive with no communication. Nothing meant anything to him. He was very ritualistic, spinning constantly. In the early going I wondered if I should leave well enough alone, but I thought every child should have a chance. I couldn't give up on him, so I kind of became his advocate."

If the airlines weren't in such a financial state Becky would be at the top of their list for birthday and Christmas cards. From Little Rock to east Tennessee she redefined the term Frequent Flyer.

Many times she traveled with an entourage. New University of Arkansas football coach Bobby Petrino would be well-advised to solicit Johnson's services for recruiting. She rounded up a couple of topnotch special education gurus to assist in developing a program for Rex. They did and Team Rex was ready to rumble!

The goal was to get Rex where he was capable of living in the community and attending a public school. Easier said than done. Progress was slow. For every inch gained Team Rex seemed to be thrown for a ten yard loss. There was an attempt to transition Rex into the community. That lasted two weeks.

Rex's issues didn't surface periodically; they presented themselves every waking second. Finding a provider to assist was difficult, and the school system had no intention of ringing its bell.



Happy birthday Rex!

"We just saw it through," said Johnson. "There was a lot of heartbreak and frustration, but slowly Rex made headway.

"We finally got things worked out with Rex's schooling, and boy did it take some wrangling! There were all the Individual

RESCUING REX...cont.



Merry Christmas.

Education Plan meetings. They never could answer all my questions, so the superintendent started coming; it did speed things along."

The saying "It Takes a Village" is true in Rex's case. As time passed a lot of people got involved. Through the behavioral issues people saw something good, something that would not allow them to temper or cease their work with him. The McCain and Obama campaigns would be envious of the Circle of Support Rex accumulated.

"You couldn't possibly name all the people who helped Rex along the way," said DMRS East Regional Office Transition Director Terry Henley-Jordan. Jordan is a former DMRS regional monitor and



Where's the keys?

worked with Rex. "The staff at Greene Valley did a tremendous job helping him move into community life. They were with him every step of the way laying the groundwork for his much-needed structure.

"We work with people, not for them. Rex had all the pieces in place for a successful move to the community, but I don't think it would have worked without him eventually

realizing what he could get out of community life. He saw what the community could do for him."

"I can't tell you how many people have contributed," said Johnson. "The staff at Greene Valley and the DMRS East Regional office, people in the Greeneville and Knoxville communities, support staff, school officials and so many more were the most wonderful people in the world. There are enough superheroes in Rex's life to fill a comic book!"

Melissa Landis wouldn't refer to herself as a superhero, but the role she has played in Rex's life qualifies her to wear a cape rather proudly. Landis is British and has only been in the United States nine years. Marriage brought her to the states, her husband is from Knoxville.

Landis has spent 16 years working with persons with developmental disabilities. While studying nursing in college she



Best friends, Rex and Melissa Landis.

volunteered at a facility similar to one of Tennessee's developmental centers. Basically, on the first day her career was signed, sealed and delivered. She's worked in group homes, institutions, served as a personal assistant and worked for agencies. Presently she is the northeast regional administrator for statewide agency Community Connections.

"I don't know if it was my calling, but it's all I ever wanted to do," said Landis. "The work has been hard at times, but there's tremendous satisfaction. You see the progress made by the persons you work with and their lives being enhanced. I can't think of a more rewarding profession."

"You would be hard-pressed to find anyone

in our field who is more dedicated than Melissa," said Community Connections East Tennessee Area Director Kris Zink. "It's not a job for her. She is such a strong advocate for the persons we serve. She has touched many lives and made them better. We are fortunate to have her."

How did Rex's and Landis' paths cross? The third time was charm. Rex finally transitioned out of Greene Valley permanently – with five behavior analysts in tow – and Knoxville became home. Through Community Connections Melissa served as his Individual Support Coordinator.

"When I first met Rex he was having a great deal of difficulty handling his behaviors," said Landis. "However, just like everybody else I took into consideration his childhood. He had virtually no chance from the beginning and I wanted to help. He just tugged at my heart and I became attached."

Landis eventually left Community Connections but remained in Rex's life as a natural support, visiting him frequently and attending all his meetings. Shortly before entering high school Rex turned 18 and came out from under the Department of Children's Services umbrella. He needed a conservator. The go-to girl was Landis. It was Rex's Circle of Support that requested she serve. She accepted of course, and of course she does it for free.

"Oh, that was a no-brainer," said Johnson.



Mother Teresa in her prime would have gotten a challenge from these ladies. Rex with (L) Becky Johnson and Melissa Landis.

"None of us would have had it any other way. Melissa's relationship with Rex has always been special. She was the perfect person for the job."

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RESCUING REX...cont.

Rex entered West High School in Knoxville, taking special education classes. Round one of high school didn't go too well – he pushed down a classmate. Exit West and enter Ridgedale, an alternative school.

"I nearly had a nervous breakdown when Rex was sent to Ridgedale," said Landis. "All I could think of was that this was a place for behaviorally-challenged students and with Rex's aggressiveness, this was not a good situation. Let me tell you, I was certainly wrong about that!"

Rex flourished at Ridgedale. The school was more structured and the kids weren't afraid of him. He had to adapt. His behaviors improved, as well as his work in classes. Landis worked on getting him a job, and before long he was delivering mail and picking up recycling two hours a day at the headquarters of Knox County schools.



Rex and his staff at high school graduation.

In May Rex graduated from high school, twice. Hey! That's a nifty achievement for anyone! He got his diploma from Ridgedale, and then Landis wanted him to have the opportunity to graduate from a regular school with his peers. Officials at Karns High in Knoxville offered the mortarboard and gown. They should have offered valium to Becky and Melissa.

Picture the University of Tennessee's cavernous Thompson-Boling Arena and more than 400 graduates taking part in a more than three hour ceremony. Picture two ladies perspiring profusely, clasping hands so tight circulation has nearly shut down and eyes, seldom blinking, focused the entire time on Rex.



The Graduate.

"It was nerve-wracking, time stood still," said Johnson laughing. "Would Rex sit for such a long time? Would he simply get up and walk out? We wanted this so much for him, especially Melissa. We thought it would be ok, but with his past, oh my."

Rex graduated – and he didn't push down the principal when he handed him his diploma. He also probably didn't notice the EMS guys giving Johnson and Landis oxygen when the ceremonies concluded.

"Everything came off great, a touchdown!" said Landis, who has never been to a Big Orange football game. "Rex walked out with the other kids and sat calmly the entire time. He was the very last one to graduate. He walked up the steps and handed the principal his card and took his diploma."

Then something special occurred. A Hallmark moment unrivaled! Everyone in Thompson-Boling Arena stood up and applauded. A standing ovation for a kid who 22 years ago entered the world with as much chance at succeeding as an overweight one-legged running back lining up in Phillip Fulmer's backfield. Rex strolled to his seat grinning from ear to ear. Got Kleenex?

Following graduation around 20 Circle of Supporters, past and present direct care staff and their families and friends gathered at Rex's house for pizza and sodas. The kid who at eleven-years-old

had communicative skills of one year, two months, walked around saying "Pizza please."

Rex's verbal ability is limited, sign language is prominent. There is familiarity with his direct care staff as the all-male team has been with him for some time. They play ball and go bowling and fishing. He attends church every Sunday. Rex is treated like a normal guy.

A job search is underway. Just last week Rex had a vocational assessment. Landis hopes for something repetitive that will keep him active and wear him out. Physical labor in a warehouse would be ideal. She's excited about his future.



One of the gang.

"Life will always be a challenge for Rex, but with the right staff he can do whatever he wants to do. He'll let you know what he wants. All we have to do is follow his lead. The past few years have been a roller coaster and I wouldn't trade a second. I look forward to being with Rex for a long time and watching him continue to defy the odds."

Last week Rex attended a Tennessee Smokies baseball game with some of his direct support staff. The Smokies play in Knoxville and are a minor league affiliate of the Chicago Cubs. Rex sat through the entire game, enjoying the fun – one of the guys.

Not bad for someone who was thrown such a wicked curve ball in the first inning of life.

Appreciation to Mrs. Becky Johnson and Mrs. Melissa Landis for contributing to this story. Photos courtesy of Mrs. Landis. ■

F · R · I · E · N · D · S



Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities

Behavior Analysis Clinic Seeing Children as Young as Three Years

The Vanderbilt Kennedy Behavior Analysis Clinic, which serves families who have a child with an intellectual or other developmental disability and who also engage in challenging behaviors, is now beginning to work with children as young as 3 years. The upper age limit continues to be 18 years.

“Many children and adolescents with disabilities have behavior problems that interfere with typical development and learning,” said Nea Houchins-Juarez, clinic coordinator. “We moved our minimum age from 5 to 3 years old to help support families and children when intense challenging behaviors are initially observed after diagnosis of a developmental disability--rather than having a family wait until age 5, which can lead to even more intense

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TENNESSEE DISABILITY COALITION

Family Voices Special Health Care Needs Survey

Family Voices Special Health Care Needs Survey

In the fall of 2006, Family Voices of Tennessee, a program of the Tennessee Disability Coalition, worked in collaboration with Title V (Children's Special Services) to conduct a Children & Youth with Special Health Care Needs Comprehensive Survey. Approximately 6,200 surveys were mailed out to families enrolled in Title V (Children's Special Services) and Family Voices of Tennessee database. The data were analyzed by the Vanderbilt School of nursing under the direction of Dr. Melanie Lutenbacher, PhD, MSN, APRN. The Comprehensive Survey was conducted to:

- identify the unique needs of children and youth with special health care needs (CYSHCN).
- obtain statewide data about TN CYSHCN.
- identify the areas where the system is working well and

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Tennessee's Developmental Disabilities Network

Accessible, Affordable Houses and Building Visitable Homes

The Tennessee Council on Developmental Disabilities funds the Tennessee Disability Pathfinder Information and Referral Office at the Vanderbilt University Kennedy Center. Pathfinder offers invaluable data on possible service needs or gaps across disability categories. According to their data, requests for housing information have been one of the top five most needed service categories every quarter from 1999 to 2007. The number of housing requests during that time was 878. Low-income and accessible housing were the most frequent housing requests. There were also a significant number of requests for housing repairs, ramps and ways to make an existing house more accessible.

In Fiscal Year 2007, the Tennessee Family Support Program served 6,068 families. The fifth most requested service, at six percent, was home modifications. Family Support funds were used by 240 people to make accessibility modifications to their homes. Lastly, one percent of Family Support funds were spent on home repairs: 32 people made significant repairs to their homes.

Tennessee Housing Development Agency (THDA) Housing Trust Fund \$10 Million Competitive Grants funded 34 applicants, each of whom will provide affordable housing to very low income Tennesseans. In addition to the income requirement, trust fund projects must serve the elderly (60 years and over) or people with special needs. Special needs are defined as Tennesseans who face extraordinary barriers when seeking to obtain or maintain adequate affordable housing that is appropriate to their needs. Two of the 34 successful applicants will use THDA funds for reconstruction/new construction of 19 units using universal design principles. United Cerebral Palsy (UCP) of Middle Tennessee received Competitive Grant funds for the statewide Disability-related Home Modification and Housing Assistance Fund. UCP will provide low cost, disability-related home modifications and repairs specific to the needs of people with severe disabilities who do not qualify for supports and services through the state's existing Medicaid Waiver Programs.

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Vanderbilt...cont.

challenging behaviors.”

Parents, or other care providers, and their child visit the clinic for an initial functional behavior assessment. During a second visit, families work with clinic staff to develop and refine a behavior intervention plan that is individually tailored to the needs of the child. Clinicians then work with the family in their home for the next month, teaching the skills needed to minimize the child’s behavior problems. Typically, the majority of behavior problems are reduced by 90% or greater after taking part in the program.

Services are provided by Board Certified Behavior Analysts. The Clinic also is a training site for graduate students in the Department of Special Education Department at Peabody College.

The clinic is a joint venture among the Vanderbilt Kennedy Center, Peabody College, and Vanderbilt University Medical Center.

For information on fees and services, call (615) 322-9007, or e-mail n.houchins-juarez@vanderbilt.edu. ■

TDC ...cont.

areas needing improvement.

The United States Department of Health and Human Services, Maternal Child Health Bureau’s six (6) national performance measures which address:

- Insurance Coverage
- Medical Home
- Coordination of Care

- Access to Screenings
- Transition to Adulthood
- Family Impact (the impact on the families’ finances, time spent with other family members, and community involvement)

Recently Family Voices of Tennessee staff has held four town hall meetings across the state to share what has been learned and to obtain reaction to the survey results. Information from the Needs Survey and the town hall meetings may be used by Children’s Special Services, Family Voices, and others to direct policy, program, and advocacy efforts on behalf of families and children.

Some of the results from the survey and town hall meetings are below:

- Most families reported a lack of coordination of care, and had to leave their community for their child to receive services.
- As the age of the child increased, the overall coordination and satisfaction with professional help in coordinating the services decreased.
- Family may pick insurance plans based on the doctors and therapists needed by a CYSHCN, sacrificing the best interests of other family members.
- Several families reported that their child with special health care needs had “maxxed” out their private insurance.
- Families reported changing jobs every two years to avoid “maxxing out” insurance.

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TCDD ...cont.

Separate from the Competitive Grants program of the THDA Housing Trust Fund, the THDA Ramps Program continues through a grant to UCP of Middle Tennessee to construct ramps for homes needing to be more accessible. Since the program’s inception in 1999, UCP has constructed 1,062 ramps. To learn more about the THDA Housing Trust Fund go to www.thda.org and click on Housing Trust Fund.

THDA’s Housing and Urban Development (HUD) funded HOME program, a housing production and preservation program, contains a special needs set-aside of ten percent of THDA’s annual allocation. Special needs projects are broadly defined as those that include, but are not limited to, housing designed for persons with an unusual need due to a condition that can be either a permanent or a temporary disability.

The THDA Consolidated Plan for Housing & Community Development cites the following: both the elderly and disabled are prone to higher incidence of housing problems, which may be affordability, structure or both.

In AARP’s *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, responses from 1102 individuals were discussed. All respondents were over 50 years old and experiencing disability of some kind (physical mobility, vision impairment or hard of hearing, cognitive or emotional disability). The report found that persons 50 and older with disabilities strongly prefer independent living in their own homes to other alternatives. They also want more direct control over which long-term supportive services they receive and when they receive them. On average, people with disabilities aged 50 and older give their community a grade of B- to C+ as a place to live for people with disabilities. One policy implication noted by the authors was to reduce the barriers to “aging in place” for persons with disabilities. Specifically mentioned were funding for home modification programs and incentives for builders to incorporate universal design into homes in order to improve independence and access for persons with disabilities and their families.

The AARP report, *Beyond 50.05: A Report to the Nation on Livable Communities: Creating Environments for Successful Aging*, discusses the impact of home design on independence, engagement and successful aging. People age 50 and older who said they live in a home that is not able to meet their physical needs as they age scored lower on several key indicators of successful aging. The report specifically identified two main ways to change the housing stock to address the needs of an aging population – home modifications and improved new home design.

Interestingly, the report noted that while home modification is critical for those who do not wish to move from their existing homes, a recent Brookings Institution report showed that almost 60 million more housing units will be needed by the year 2030 to serve the nation’s growing population and to replace some of the

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TDC ...cont.

- Families reported having to reduce their assets, and gross income to poverty level to qualify for state insurance (TennCare), and other state and federal programs that provide assistance to children with special health care needs or disabilities.
- There was a great need expressed for respite services for CYSHCN and aging parents.
- Youth transitioning to adult services can be placed on long waiting list for services.
- There are many gaps in the coordination of care and provision of services for youth transitioning to adult services.
- Most families reported that their child's doctor did not discuss transition with them before their child turned 18.
- Some families feel that the deep cuts being made in the MR waiver program is disenfranchising their child by disallowing them the opportunity to live independently, make their own choices, or to receive appropriate health care services. "I feel that I don't have a voice because in my opinion [state officials are] not listening and do not care."
- Some families feel that most adult doctors do not like to provide medical treatment to adults with special health care needs.

For additional information about the survey and town hall meeting results, contact either Donna Graham at donna_g@tndisability.org or Julie Sullivan at julie_s@tndisability.org or by phone at 1-888-643-7811. ■

TCDD ...cont.

nation's aging housing stock. This wave of new housing will have to serve the future needs of residents of varying ages and varying abilities for several decades. This represents a significant opportunity to incorporate accessible features into new home construction through either universal design or Visitability.

Further, the National Association of Home Builders 50+ Housing Council reported some findings on their Web site from their research report entitled, *Profile of the 50+ Housing Market*. One finding of note is that more than 75 percent of new homebuyers in age-qualified, active adult communities chose their home because of its room layout and the design of the unit.

Lastly, in 2005 the U.S. Conference of Mayors passed a resolution recognizing the importance of Visitability and visitable homes.

The need for accessible and affordable housing for people with disabilities was listed as a significant systems issue in the council's new five-year state plan in 2006. Therefore, a goal was included to develop and implement a statewide visitable home building program.

While it does not provide a comprehensive solution to the growing problem, building accessible new homes is an economical way to increase the number of accessible homes in Tennessee. Adding accessible features to an existing home can be cost prohibitive, but there is minimal cost associated with adding accessible features to new home construction.

Visitable features include a step-free entrance into the main floor; a bedroom, a kitchen, entertaining area and a wheelchair-friendly bathroom all on the main floor; and every interior door on the main floor provides a minimum of 32 inches of clear passage. Building accessible new homes would increase the number of accessible homes available for people with disabilities and others in the state without adding significant cost.

A program that has been very successful in

promoting construction of first level accessible homes is the EasyLiving Home^{cm} program in Georgia. It is the nation's first voluntary certification program that specifies first level accessible features in new home construction. The program was developed by the Georgia Developmental Disabilities Council with assistance and cooperation from the Georgia Homebuilders Association and other groups that were interested in the project. The program includes a broad coalition of public and private organizations that partner to encourage and assist homebuilders throughout the state to build visitable homes in all price ranges.

Our council has just established a statewide EasyLiving Home^{cm} program to promote construction of first level accessible (Visitable) homes. This program will fit the unique characteristics of Tennessee, including its significant cultural and geographic differences.

As part of the Tennessee program, a broad coalition of public and private organizations will be built that will work together to increase the number of Visitable new homes built throughout the State. This group will work closely with the Visitability Workgroup already established by the Council. A voluntary certification process that recognizes and certifies builders in the state who build first level accessible homes will be created and implemented. The project also will include an advertising and marketing component as an incentive to builders who include these features in their new home construction. ■

Medical Message...cont.

Many people search the net for health information. While this is productive it is important to remember that not everything in print is necessarily true or applicable to your health issue. A good place to begin the search is a booklet titled *Patient 101*, www.jointcommission.org/GeneralPublic/patient_101.htm. Next month we will address the issue of good health in people with mental retardation. ■

Securing the Future, Bridging the Gap

School to Work | *Transitions for Young Adults with Disabilities*

Key Note Speaker What Works
Conference Austin, Texas 2006



John Hager, Assistant Secretary Office of Special Education and Rehabilitative Services with an attendee.

Key Note Speaker iMatter
Conference Santa Fe, New Mexico 2007



Michelle Lujan Grisham, was appointed Secretary of the Department of Health by Governor Bill Richardson 2004-2007.

Speaker iMatter
Conference Santa Fe, NM 2007



Alfredo Vigil, MD, Secretary, New Mexico Department of Health with Marge Brown and Dr York, Ed.D Community Options Board Members.

Community Options, Inc. 3rd Annual Conference

September 7-10, 2008

The Hermitage Hotel | Nashville, Tennessee

Community Options' conferences provide a national forum that promotes greater social and economic participation of people with disabilities, and results in a consensus-based plan of action.

Person with a disabilities, parents, educators, and professionals are invited to attend to discuss current issues regarding Transitional Services or the lack thereof, identify barriers, opportunities, and developing short and long term plans for local and national action and advocacy.

For more information or to register please contact:

Lisa Smith
Lisa.Smith@comop.org
1-877-875-1212

Or visit our website
www.transitionschooltowork.org

For more information about Community Options, Inc.
www.comop.org

SAVE THE DATE
TN NADD ANNUAL CONFERENCE
NASHVILLE, TN AT THE HOTEL PRESTON
SEPTEMBER 17 – 19, 2008

BREAKING THE BOXES: Integrating Health Care, Clinical Services, and Environmental Support to Promote Meaningful Lives for People with Intellectual and Developmental Disabilities

TN NADD (National Association for the Dually Diagnosed) will be sponsoring its annual conference in Nashville, TN on September 17 – 19, 2008. On the afternoon of the 17th, a professional forum will be held for psychologists and behavior analysts related to service delivery in Tennessee. On the 18th and 19th, speakers will present on a variety of topics ranging from in-home treatment for children with a dual diagnosis to comprehensive functional assessment of challenging behaviors. Presentations are designed to appeal to a wide audience including psychologists, behavior analysts, direct support professionals, therapists and families.

All are invited to attend. For more information or to get on the mailing address, please contact Bruce Davis, TN NADD president, at (615) 532-2402 or bruce.davis@state.tn.us.

COME JOIN US!





There are many acronyms and terms associated with the DMRS. In each issue of Personally Speaking we'll serve up a small portion of Division alphabet soup.

- **DME**
Durable Medical Equipment
- **HCBS**
Home and Community-based Waiver Services
- **HIPAA**
Health Insurance Portability and Accountability Act

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Personally Speaking Listens!

Personally Speaking is a Tennessee Department of Finance and Administration, Division of Mental Retardation Services' bi-monthly publication targeting DMRS stakeholders, which appears on the DMRS website. Personally Speaking is written and produced by the DMRS Office of Communications.

Got ideas or opinions? Send them our way!

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